



# RARE DISEASE DAY WEBINAR

Bringing Canada's Rare Disease  
Drug Strategy From Vision to Reality  
**February 24, 2022 @ 12 pm EST**



Canadian Organization  
for Rare Disorders

- CORD is launching a Year of Action to bring Canada's Rare Drug Strategy from Vision to Reality. For the past two years, CORD has led consultations over two dozen roundtables and forums to forge a "working consensus" on the vision, framework, key components, and recommended actions for implementation in 2022.
- On February 24th, CORD will host Webinar 1 in our Rare Drug Strategy Implementation Series with an expert multi-stakeholder panel to deliberate the plan of action to implement the pillars of Canada's Rare Disease Strategy as a foundation for the Rare Drug Strategy.

## Panel

This webinar brings together a roundtable of diverse experts charged with reimagining a "made-in-Canada" framework for rare disease drugs, from discovery to sustainability:

- Étienne Richer, Associate Scientific Director, CIHR Institute of Genetics
- Thierry Lacaze-Masmonteil, Maternal, Infant, Child, Youth Research Network
- Fred Little, Country Lead, Rare Disease Canada, Pfizer
- Sandra Anderson, Senior Vice President, Innomar Strategies
- Paul Wilton, Vice-Chair, CORD
- Health Canada, TBD

## Agenda

- **How We Got Here and How Do We Get to Where We Want to Go**
  - Why does Canada need a national Rare Disease Drug Strategy?
  - What is Status Quo; what has gotten better and what are priority challenges?
  - What are case examples of current and emerging rare therapy challenges?
  - What is a "Smarter Way Forward?"
- **Vision and Actions**
  - 5-, 3-, and 1-Year Vision and Objectives
  - Three Essential Pillars of Action: Infrastructure, Drug Supply, and Patient Engagement
- **Reimagining How to Get There**
  - What Now: How are innovative rare disease drug assessed using current pathways, agencies, tools, hand-offs, and trade-offs?
  - What Next: Reimagine a "better way forward" to address uncertainties (outcomes, eligibility, system capacity, data management), adjust timelines relative to urgency, and promote sustainability (valuation, funding, budget impact)
  - Recommended Priority Actions: What are priority investments in pathways, infrastructure, capacity building that will have impact today, next three years, and in five years

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